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Powering Change Through Partnership

TESTIMONY OF TINA CAMPANELLA, EXECUTIVE DIRECTOR
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DISTRICT OF COLUMBIA

RE: SERVICES AND SUPPORTS FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES IN THE DISCTRIC OF COLUMBIA

COMMITTEE ON GOVERNMENT REFORM
US HOUSE OF REPRESENTATIVES

REPRESENTATIVE THOMAS M. DAVIS
CHAIRPERSON

Friday June 16, 2006

Good morning Chairman Davis and members of the Committee. My name is Tina Campanella and I am the Executive Director of Quality Trust for Individuals with Disabilities, an independent nonprofit advocacy organization for people with developmental disabilities in the District of Columbia (DC). Thank you for this opportunity to testify before the Committee on Government Reform. Quality Trust exists to advance the interests of people with developmental disabilities in DC. Our organization is a product of the 2001 Settlement Agreement in the Evans v. Williams class action lawsuit. We represent all citizens with developmental disabilities in DC, not only the 665 Evans class members. An important part of our role is to ensure there is an independent voice for people with developmental disabilities in the DC.

The situation for people with developmental disabilities in DC is very troubling. The current structure and framework for services is not working well at all. The Mental Retardation and Developmental Disabilities Administration (MRDDA) is poised on the verge of receivership. The current MRDD waiver is due to expire in the fall of 2007 and without serious efforts to develop a viable and comprehensive plan for services funded through the waiver that addresses the increased national expectations for performance and quality, it is conceivable

that the federal government may not renew the city's 1915(c) Home and Community Based Services (HCBS) waiver.

Our efforts in day to day action and testimony before the DC City Council have focused on how to address both the pressing and immediate needs of people supported by MRDDA as well as the persistent structural problems that have plagued this agency. While Forrest Haven was closed in 1991, the community system created and still in existence today relies heavily on the same program and funding structures used at the institution – the Intermediate Care Facilities for People with Mental Retardation (ICF's/MR). The Home & Community Based Services (HCBS) Waiver program that exists to fund community based alternatives to Intermediate Care Facilities for People with Mental Retardation (ICF's/MR) has been underutilized. The critical question is how to make fundamental changes in the organization and operation of the service system. Quality Trust has used our advocacy experience to inform our recommendations for change. I have included with my testimony a four page working document that describes the broad changes needed within the DC service system to make services responsive to the needs of the people it supports.

We want to commend Councilmember Adrian Fenty, chair of the DC City Council Human Services Committee for his leadership and focus on accountability. I would also like to recognize the efforts of Deputy Mayor Brenda Donald Walker. Following her appointment in November 2005, she immediately began identifying ways to improve the system.

The DC system cannot be improved without bold and dramatic change. The difficulties extend well beyond the individual appointed as administrator. The fragmented structure of the administration, funding and enforcement functions is at the root of problems with performance and accountability. We experience this directly through our advocacy work, and have documented it in our report, "In Search Of Real Lives and Real Choice". In one instance not included in our report, a QT advocate worked with a woman who was living in an apartment dilapidated to the point of being a health risk. Despite intense efforts by the advocate and personal intervention from the court monitor and the Administrator of MRDDA it took nearly seven months to successfully transition this woman into a new living arrangement.

Our recommendations target essential elements of a functional system. These recommended actions will not fix the situation quickly, but they will advance the dialogue about how to bring greater accountability to the administration, funding, and oversight of services and supports to people with developmental disabilities. We highlight the following issues as critical starting points for fundamental change:

- A comprehensive plan to manage Medicaid dollars from all relevant funding options such as HCBS waiver and ICFs/MR funding and to

coordinate functions between MRDDA and the Medical Assistance Administration (MAA) is essential. Waiver funding currently represents less than 7% of Medicaid outlays on behalf of people using MRDD services in the city. The city must transition dollars spent supporting people in ICFs/MR into more integrated community services financed through the HCBS waiver program.

- Preparing the waiver application due to the CMS in spring 2007 must be a priority. We understand that the city has recently secured the assistance it needs to ensure that this task is completed. We will continue to emphasize and advocate for the meaningful involvement of people with disabilities, their families and advocates as well as other key stakeholders in this process. We look forward to working with the city on this effort.

- A coordinated strategy to ensure that providers enter the system with prerequisite qualifications and that performance over time is tracked to identify areas where difficulties are encountered is needed. Responsibilities for licensing, certification and quality monitoring now spread between MRDDA and the Department of Health through its Health Regulatory Agency (HRA) need to be linked and closely coordinated, preferably with one agency taking the lead. Any restructuring needs to ensure that MRDDA has adequate input into these functions as well as access to and control of information and cumulative data. As noted before, the city risks not qualifying for renewal of its DD waiver program unless it is able to articulate a coordinated quality management strategy that is consistent with the Center for Medicaid and Medicare Services "Quality Framework" required in the new HCBS waiver application template.

- Ensure case management practice is grounded in a tradition of individual advocacy and support for people's right to create lifestyles of their own choosing to the greatest extent possible. Case Managers need to actively pursue whatever it takes to provide individualized supports while assuring that standards for quality are met.

- According to D.C. Law (D.C. Code § 7-1304.13(a)) all individuals who are receiving residential services (committed or admitted) are entitled to an advocate. The structure and process in D.C. to meet this requirement is known as the District of Columbia Mental Retardation Volunteer Advocates Association, Inc. (DCMRVAA) and is part of the DC Superior Court, Family Division. This function has not been implemented as envisioned as it has no dedicated funding. Funding for this function has been included in the current budget request and must be funded.

- Finally, funds and efforts should be devoted to developing a strategy for working together with families and providing support to people in their

family home. In-home family supports provide an important alternative to group living arrangements and need to be part of DC's long term strategy for services and supports. The framework for funding exists but will remain unused without specific efforts to develop the provider capacity needed to deliver this type of support.

We are encouraged that DC has secured assistance from Ms. Kathy Sawyer, an experience administrator within solid expertise in this area. However, we are mindful that these problems are substantial and cannot be fixed overnight through policy development and planning. Further, there is great urgency to move forward quickly to ensure people with developmental disabilities are protected from any additional harm and supported to live full and productive lives. A solution requires everyone to remain clearly focused on the immediate planning and intervention needed to provide adequate and reliable supports for people **today** while designing and implementing the structure and capacity needed for the future. In our advocacy role we are committed to working with the city administrator, Deputy Mayor Brenda Donald Walker and staff of MRDDA to ensure people get the supports and services they need.

Thank you again for the opportunity to testify and I will be happy to answer questions.

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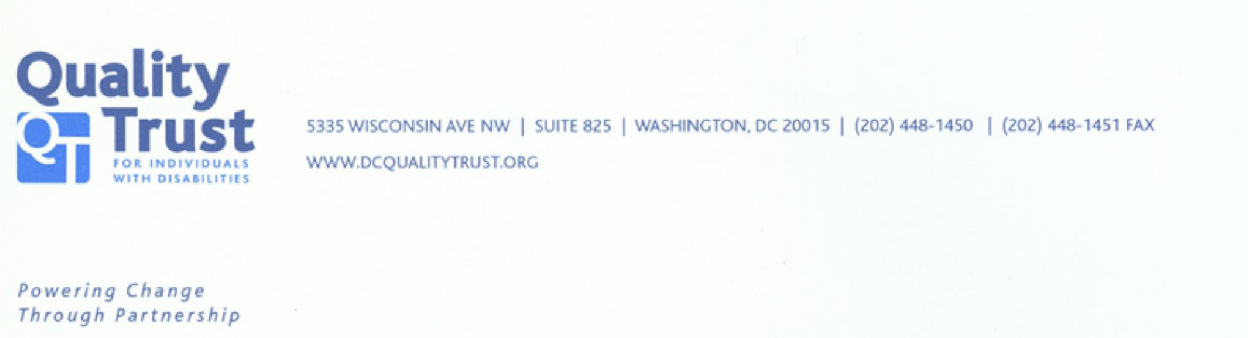

Initial Steps toward a Functional
Developmental Disabilities Service System in DC

Background

In 2003, Quality Trust for Individuals with Disabilities initiated a project designed to demonstrate how people with developmental disabilities, living in Washington, DC, might experience more integrated and fulfilling lives. This project focused in on the specific needs of five (5) individuals with developmental disabilities supported by the Mental Retardation and Developmental Disabilities Administration (MRDDA) in the District of Columbia (DC). The lessons learned from involvement in the lives of these five people resulted in a project report, "*In Search of Real Choice and Real Lives"* which presented project conclusions and comprehensive recommendations for reform within the DC service system.

After the project report was released in January 2006, Quality Trust continued to focus its attention on defining the broad changes needed within the service system to make services responsive to the needs of the people it supports. From our advocacy experience and the recent reports filed by Court Monitor in the *Evans v. Williams* litigation, it is clear that the current system is not working and that improvements in system performance will not occur without significant and fundamental change. The city needs to make a firm break with the service traditions of the past and address the many serious challenges it faces with bold and decisive action. The specific steps proposed here represent immediate, specific short-term actions that can be taken to begin the process toward reform. It is important to remember however, that these steps outline just the beginning of a longer range strategy for broad based, systemic change.

Recommended Action Steps

1. Ensure a clear focus on the people being supported in legislation, policy and practice.

Supports and services must be grounded in principles that (a) recognize family

and individual competence; (b) promote self-determination and living, working and attending school in the least restrictive living environment as basic rights of all people with developmental disabilities and (c) endorse individual choice. These foundational principles on which DC can build a framework for services should appear in both legislation and administrative policies. New legislation is needed to replace the current statutory foundation for services known as the "Mentally Retarded Citizens Constitutional Rights and Dignity Act of 1978".

Once published, the statement of principles must be imbedded in practice. Central to reform will be replacing the congregate, program models and approaches reflected in the 1978 law with more individualized, person-centered approaches to supports and financing. Specific plans for supporting providers (both programmatically and fiscally) will be needed to facilitate the transition to the individually designed and person directed support approach.

2. Unify responsibility for all aspects of service administration with authority to cut across agency and departmental distinctions.

Bringing together in one District agency the responsibilities for planning, implementing, administering and financing services and supports for people with developmental disabilities is crucial to fixing what ails our service delivery "system". As it now stands, relative to Medicaid funding, MRDDA is responsible for the design and implementation of supports for people with developmental disabilities and the Medical Assistance Administration (MAA), within the Department of Health (DOH), manages and controls funding for those supports. This simply does not work. A comprehensive agreement between MAA and MRDDA that details how Medicaid long-term service dollars will be managed on behalf of people with developmental disabilities is needed. Centralizing accountability is essential to resolving the barriers that have impeded progress for so long.

The administrative arrangement we propose has ample precedents. Indeed, a 2002 survey commissioned by the federal Centers for Medicare and Medicaid Services (CMS) found that in two-thirds of the states day-to-day management of Medicaid MR/DD ICF/DD and waiver services had been delegated to the state MR/DD agency.[1] This type of arrangement is fully consistent with current CMS polices as underscored by the recently released instructions and technical guide that accompany the agency's new Section 1915(c) waiver application template.[2] The guide book states that:

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[1] Appendix A, ***Summary of Results: National Quality Inventory Survey of HCBS Waiver Programs***, prepared by for the Centers for Medicare and Medicaid Services by the Human Services Research Institute and The Medstat Group, Inc., 2003

[2] ***Instructions, Technical Guide and Review Criteria: Application for a Section 1915(c) Home and Community-Based Waiver***, Disabled and Elderly Health Programs Group, Center for Medicaid and State Operations, Centers for Medicare and Medicaid Services, November 2005.

> CMS recognizes that it may be efficient and effective for a state to locate the operation of a waiver with an agency other than the Medicaid agency and link the delivery of waiver services to other federal, state and local programs…

When a state chooses to delegate responsibilities to an agency other than the single state Medicaid agency (SSMA), the SSMA (MAA in the District) nonetheless must supervise the performance of the functions performed by the operating agency. However, the waiver technical guide makes clear that

> Supervision does not mean that the Medicaid agency must review and approve each and every action taken by another entity. It is expected that the Medicaid agency will conduct or arrange for the periodic assessment of the performance of other entities in conducting the waiver administrative and operational activities to ensure that the waiver is operated in accordance with the approved waiver and applicable federal requirements.

With CMS's approval, states have developed various approaches to ensuring that their state Medicaid agencies have acceptable approaches to carrying out their performance oversight roles.

While there is a Memorandum of Understanding between MRDDA and MAA regarding implementation of the Medicaid waiver and an implementation arrangement that on the surface reflects this type of arrangement, in practice it has not worked as a partnership. As a result, basic information about service usage and funding is not available and is not used to guide current and future administrative activities. In addition, the regulatory control exercised by the Health Regulatory Agency (HRA), also within the DOH, in the certification of ICF/DD providers further fragments policy and administration. Close collaboration and coordination from HRA is critical to shift the system from the current "institutional bias" to the type of individualized and community oriented system we envision.

All agencies share some responsibility for this dysfunction. This disjointed and fragmented structure for key responsibilities leads to indecisive decision-making and a poorly managed service system. Consolidating the administrative and oversight responsibilities for Medicaid funded supports will go a long way toward promoting a clear, shared vision for using Medicaid funding to create high quality, cost effective services. Accomplishing this will require bold leadership.

3. Develop a comprehensive strategy for establishing and enforcing a clear set of performance expectations.

Setting and enforcing performance expectations plays a critical role in bringing performance in line with minimal expectations. There needs to be a coordinated strategy for ensuring providers enter the system with prerequisite qualifications,

periodic assessments are made to ensure basic expectations are met and that performance over time is tracked to identify areas where difficulties are encountered. In addition, there is specific urgency for developing a comprehensive quality management strategy for HCBS waiver services consistent with CMS's "Quality Framework" in order to qualify for renewal of the city's Section 1915(c) waiver in 2007.

Responsibilities for licensing, certification and quality monitoring now spread between MRDDA and the DOH Health Regulatory Agency (HRA) need to be linked and closely coordinated, preferably within one agency taking the lead. Operating procedures need to clearly spell out how information will be shared and responsibilities for working to remedy performance issues. Finally, there need to be clear sanctions and consequences to implement when performance problems persist and are not corrected.

A functional performance measurement system for is also needed for MRDDA and its employees with incentives for hitting standards and penalties for poor performance and poor outcomes. Performance benchmarks for critical operations must target areas that reflect priorities for the people who depend on MRDDA for support. Strategies for measuring performance should include independent assessment – at least from another city agency but ideally from an independent, nongovernmental organization.

Along with setting performance expectations, increasing the quality, diversity and number of services providers who offer the full range of supports and services, especially those eligible for waiver funding is critical. Efforts to expand provider capacity can play a key role with implementing improvements through:

- Ø Shifting performance expectations from the "comprehensive" one stop model to an individual support approach to service delivery. The ability to customize services and support to individual needs and ensure that people are not over or under served must be seen as a fundamental performance criterion for provider operation.

- Ø Developing incentives for providers to meet national performance standards. The best and most respected providers throughout the country have integrated practices of benchmarking and external evaluation into routine operations. A functional system would encourage and reward providers that pursue strategies that could enhance the effectiveness and efficiency of operations to produce the best possible outcomes for the people being supported.

- Ø Developing specific plans, incentives and support strategies to accelerate transition from traditional, congregate services to individual support agencies within the existing provider community. Making this type of change in the approach to service delivery rarely occurs without a

significant commitment of time and resources. Providers will need a variety of supports and incentives to begin the shift in practice. Once begun, the transition will only be successful if there are clearly outlined performance expectations and deadlines to ensure implementation.

4. Require annual reporting that accurately describes people, issues and challenges and links to identified priorities and performance benchmarks.

Annual data reflecting critical performance indicators across the system (such as numbers of people approved for specific services, numbers of people actually accessing those services and numbers of people requesting services that may not be available and why) provides the foundation needed for future planning. This type of data collection and reporting is the only way to reflect the priorities for individual and families that need to be addressed and to accurately describe the strengths and limitations of the system of support. Such data is also essential to inform administrative and budgetary decisions made by the executive and legislative branches of government.